

EXEMPLARS OF SUCCESSFUL ALZHEIMER'S DEMONSTRATION PROJECTS

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Abstract

The Alzheimer's Demonstration Program was established in 1991 to develop models of home and community-based care for persons with Alzheimer's disease and their families. After more than ten years of program experience and evaluation, the Alzheimer's Demonstration program has generated significant information about how to work successfully with families coping with Alzheimer's disease. In particular, the Demonstration program has been very successful in developing innovative program models and approaches to serving traditionally underserved populations such as ethnic minorities, low income, and rural families. Of particular interest is the significant number of successful project components that are replicable in a variety of community settings. This article provides detailed programmatic and replication information for five successful Alzheimer's Demonstration program models: Mobile Day Care; Rural Geriatric Dementia Evaluation, *El Portal* services for Latinos, Client Advocates, and AL-CARE services for clients who live alone.

Keywords: Alzheimer's disease – Minorities – Service Delivery – Caregivers – Dementia – Aging – Rural – Program Development – Living Alone

Exemplars of Successful Alzheimer's Demonstration Projects

INTRODUCTION

The Alzheimer's Demonstration Program was established in 1991 to develop models of home and community-based care for persons with Alzheimer's disease and their families. After more than ten years of program experience and evaluation, the Demonstration program has generated significant information about how to work successfully with families coping with Alzheimer's disease. In particular, the Demonstration program has been very successful in developing innovative program models and approaches to serving traditionally underserved populations such as ethnic minorities, low income, and rural families. Of particular interest is the significant number of successful project components that are replicable in a variety of community settings. This article provides detailed programmatic and replication information for five successful Alzheimer's Demonstration program models: Mobile Day Care; Rural Geriatric Dementia Evaluation, *El Portal* services for Latinos, Client Advocates, and AL-CARE services for clients who live alone.

To gain a more complete understanding of the unique challenges and how best to address barriers associated with serving hard-to-reach populations—that is, rural, minority and low-income communities, representatives of nine of the demonstration grantees came together to participate in a working conference. Over the course of two days, these individuals participated in a number of focus groups that allowed for a wide exchange of information about different aspects of the project development experience. Through these focus groups, detailed information was gathered about issues that each project had faced during their implementation phases as well as how each site had developed successful strategies to address them.

Numerous challenges for project success were identified through the focus group discussions. For demonstration projects in rural areas, the most essential components to success were addressing issues of isolation from technical resources, limited numbers of trained workers, expansive geographic service regions, transportation for both clients and workers, small numbers of clients in any particular community that precludes economies of scale.

Demonstration projects that had focused on serving ethnic communities identified the need to overcome both cultural and language barriers to be effective. Having the ability to communicate with potential client families in their own language was only part of the challenge that these sites faced. More importantly, these projects had to build trust within the community and found that knowledge of their cultural customs and expectations was essential to developing appropriate services.

Additionally, all demonstration projects faced the need to build service stability and community commitment to the services to ensure continuity after the federal funding and technical support ended. Thus, each site sought to create interagency and other local partnerships to ensure continuation of services for Alzheimer's families. Having identified the specific challenges each project had found, focus group participants then discussed the strategies that had been most effective in serving hard-to-reach populations. Six "how-to" themes emerged from the discussions that can be seen as implementation steps that were followed by all five of the exemplars discussed later.

The steps for developing successful services in diverse communities are:

1. Establishing trust and credibility with target populations through

organizational partnerships. Staff of the demonstration projects quickly learned that the success of their projects depended upon the endorsement of key

community leaders and the forging of partnerships with organizations that already enjoyed high credibility with potential clients in the target population. Through the development of partnerships with well-established ethnic health and social service organizations, several of the projects were able to readily gain the trust of prospective clients as well as the commitment of resources to demonstration projects.

2. **Building community awareness of Alzheimer's disease and available services.** Through the development of local collaborative partnerships, demonstration projects could become more integrated into the existing service systems, which greatly increased the awareness of Alzheimer's disease and dementia issues within the community. Additionally, the demonstration site was able to utilize the partner organizations' communication infrastructures to disseminate dementia information in a way that potential clients found more acceptable.
3. **Building service capacity.** Generally, capacity was increased by expanding capability of existing services with additional knowledge and/or creating new services. Staff knowledge was increased through cultural awareness and dementia-specific training.
4. **Creating new services.** In some sites, projects sought to develop local providers through "seed money" grants and technical assistance. In other areas, the collaboration with new partners also resulted in new services.
5. **Developing local resources.** Resources were developed at two levels. First, local providers and staff members were trained to provide new or expanded services that were either dementia-specific or more culturally appropriate. Second, community-level partnerships were developed and local funding streams accessed. Local commitment and new partnerships often prompted the creation

of effective advisory councils and coalitions of agencies able to collaborate in seeking new funding and developing new services.

- 6. Stabilizing projects and services.** When combined with strong community commitment, the collaborative partnerships, increased capacity, and expanded resources all form the foundation for this last step of transitioning from a demonstration project to a stable and ongoing service.

The five service models described in this article serve as exemplars of sites that implemented all six steps successfully and were able to effectively address the challenges of their particular target population. Each example is discussed below in a format that illustrates the implementation steps for each project that we hope will inspire replication.

GEORGIA MOBILE DAY CARE

Project Description

Georgia's mobile day care is an innovative approach to providing social day care in rural communities that may not have the resources to support their own full-time, day care program. Leaving each morning from a central location, program staff (with materials and supplies needed for the day) travel to a rural site. Depending on the needs of the community, each center is open one or two days per week, for six hours a day. Day care is held in a community building (church, senior center, etc.) in the rural community. When possible, transportation for participants is arranged through community resources. The mobile day care model allows rural communities to have their own adult day care program by sharing staff and resources that move from location to location.

Background & Rationale

State service agencies identified the need for respite designed specifically for persons with Alzheimer's disease in Georgia's rural areas as a critical social need. Georgia set out to use the Alzheimer's Demonstration funds to deliver respite in rural areas in a cost-efficient manner and with well-trained staff. The initial grant addressed the need for respite care by developing several mobile day care sites throughout Georgia. The Atlanta Alzheimer's Association chapter initially located mobile day care projects in various local chapter offices around the state and began to develop, direct, and staff these rural programs from their central state office. With experience, however, it became clear that one central agency for the entire state did not work well, and subsequent projects have been decentralized.

Project Administration

Georgia's Alzheimer's Demonstration project was created and administered by the Georgia Department of Human Resources, Division of Aging Services. Development and implementation of the mobile day care program was a collaborative effort involving the Department of Human Resources, the Atlanta and Augusta chapters of the Alzheimer's Association, and local communities and service providers.

Project Development

Specific tasks necessary for the development of a rural mobile day care site include hiring staff, identifying an appropriate location, and making arrangements for client transportation and meals. Georgia's initial step in implementing rural mobile day care was to hire a Community Development Coordinator to direct education and conduct an outreach campaign. General outreach about mobile day care occurred through human interest stories with pictures in the local newspapers, and the development and distribution of flyers throughout the community. Additionally, the community

Development Coordinator developed a community coalition and advisory board.

Membership of these groups included pharmacists, physicians, church leaders and service providers to assist with marketing and oversight. The community coalition began by providing joint educational presentations or events at community and civic meetings. The community coalition and the Community Development Coordinator spoke to local groups and service agencies concerned with elderly individuals, operated booths at local health fairs, and donated books on Alzheimer's disease to the local library. Gaining community support was essential to the success of the mobile day care services.

Initially four staff positions were required to operate the mobile day care program. The Community Development Coordinator worked three days per week and was responsible for public relations, trouble shooting for mobile day care operations, making local arrangements for educational programs and community outreach. The coordinator was also responsible for developing a coalition of community professionals and caregivers to assist in promoting the mobile day care.

A Day Center Director worked two and a half days per week at each site. The Director's responsibilities included developing program activities, supervising aides, gathering supplies, providing feedback to families about the client, and transporting staff and supplies to mobile day care sites.

A Certified Nursing Assistant (CNA) worked two and a half days per week. CNAs were hired from the local community when possible. Their responsibilities included assisting the director, assisting clients with activities (crafts, meals, toileting) and providing one-on-one contact with each client during the day.

A Case Management Coordinator worked one day per week at each site. This position was held by an experienced social worker that conducted initial and periodic functional and eligibility assessments, and assisted families with accessing other community services.

To establish a mobile day care site it was necessary to arrange for a day care location, transportation, and meals. An appropriate facility must provide adequate space that is safe and appropriate for persons with dementia during the times they are there. In Georgia, churches and senior centers have been used, but each site must be individually evaluated for accessibility considerations. Gaining the commitment and support of a host organization is critical to success of a mobile day care. Potential host organizations may require education about the needs of individuals with dementia and how to negotiate liability concerns and insurance issues.

Securing transportation for day care participants was also a challenge. In Georgia, one county had an aide who rode in the Senior Services van to pick up clients for the mobile day care program. Other transportation options may include RSVP and similar community escort services or a locally constructed transportation “tree” or network.

The provision of meals is another consideration when developing a mobile day care program. One Georgia site was located in a senior center that provided meals on-site, which reduced overall costs. Older Americans Act congregate and home delivered meal programs and Meals on Wheels programs are other resources for mobile day care meals. In some communities, the local hospital or nursing facility may be able to provide meals for mobile day care clients, particularly for those individuals with specialized dietary requirements.

Community Partnerships

A community coalition served as an advisory committee and was instrumental in building community awareness and trust. The coalition included representatives from local nursing homes, home health agencies, the Department of Family and Children services and community leaders. This group of partners directed marketing efforts,

monitored appropriateness of efforts for the community, provided access to community service links, facilitated support groups in nursing homes, and worked with the hospital to open an adult day care center. Through these efforts, coalition members became more aware of the needs of Alzheimer's families in their own community. Partner agencies had difficulty freeing up staff time for coalition meetings until they saw the positive results of teamwork.

As with all of the successful Alzheimer's demonstration projects, community partnerships were key to the overall success and long-term viability of the mobile day care program. In time, the benefits that stemmed from agencies working together were recognized. Indeed, group efforts proved to be much stronger and more successful than solo efforts.

Barriers and Obstacles

As the mobile day care program was developed, several community concerns had to be addressed. In the course of negotiating with a potential host organization about space, liability issues were a concern. Additionally, the comfort of other groups using the space shared with a dementia population needed to be addressed through education. Also, the community coalition was helpful in guiding outreach and education efforts to assure compatibility with the rural tradition of "taking care of our own."

The lack of reliable transportation in rural communities is a well-known barrier to rural service delivery of all kinds. Although mobile day care brings day care within a reasonable commuting distance, clients may still need transportation. Equipment, insurance, and driver training are all issues that frequently prove to be overwhelming for many communities. Yet, the provision of transportation remains a key element affecting the participation of families in the mobile day care program.

Project Outcomes & Benefits

Benefits of the mobile day care program can be observed at many levels. First and foremost, dementia-specific respite is now available in rural communities previously without dementia services. Another major benefit is the strengthening of staff capacity by integrating the staff into the Alzheimer's Association day care program in Augusta. Staff had been cross-trained to fill in at the Augusta center during sick and vacation days. By offering full-time positions with multiple worksite locations instead of many part-time single-site locations, more highly skilled and better-trained staff can be hired and retained. By integrating staff into the central location (Augusta) as well as the rural sites, staff reported higher job satisfaction and less isolation, and there is less staff turnover.

The provision of local employment opportunities, maintenance of local cultural norms, and improved client relations are also benefits and outcomes of this model. When possible, the program aides are hired from the local communities and work with the community development director from Augusta. Hiring from the community means that the clients often know the staff member. This relationship frequently helps to facilitate the transition from family care to the regular use of mobile day care services.

One final and important outcome is that the community coalition brings together individuals and agencies that often have not worked together previously. Their increased awareness of Alzheimer's disease filters into other community projects and broadens the community understanding of the needs of persons with dementia and the unique needs and opportunities of rural communities. For example, after the implementation of mobile day care, Alzheimer's issues were considered in designing other service spaces and a home health agency opened an office in a remote area of Georgia.

Finally, the Georgia project developed a video and manual about Mobile Day Care that is available to communities interested in starting their own mobile day care service.

Project Costs & Funding

The costs for developing and implementing mobile day care have been minimal. Most of the costs are in salaries. Less money is needed to start a new mobile program than is needed to establish a traditional adult day care center. Program costs are significantly lower when space is shared or donated and the meals are purchased as needed. The budget for activities is also nominal.

In 1999, the Georgia program had a budget of just over \$31,000 per year for the two sites operating two days per week. This budget included \$22,000 for staff positions and supplies, telephone, equipment, insurance, staff training, staff travel, and client services. The program paid for liability insurance (\$500 per year) in lieu of rent for the shared space.

New day care programs are frequently difficult to sustain because of insufficient enrollment. Georgia's mobile day care concept, however, distributes staff costs between two sites thus decreasing both the cost and the risk to each site. The success of the Augusta mobile day care, inspired Georgia to fund several new mobile day care sites, primarily using Brookdale Foundation funds for initial planning and start-up costs. The services are now sustained through a combination of client fees and support from the Georgia Department of Human Resources, Division of Aging Services.

Keys to Success

Four aspects of the project were identified as essential to its success:

1. **A well-trained, enthusiastic Community Development Coordinator.** The Coordinator conducted outreach and worked to gain community trust and

respect for the project. Trust and respect were essential to securing adequate space and developing necessary community support and partnerships.

2. **A well-developed and active community coalition.** Partnerships were vital to the success of all mobile day care programs. Community coalitions not only provide essential support and assistance to the program, they also help to establish the program as a legitimate service in the community, serve as important sources of information on local community culture, and assist with long-term program sustainability.
3. **Members from diverse areas of the community are involved.** Awareness and respect for local culture and diversity is important in ensuring that mobile day care services meet the needs of the local residents. From activity design to menu planning, incorporating diversity is essential to successful service development.
4. **Maintaining the community coalition in an active role in the project.** While many foundations and organizations offer grants to fund start-up costs for new programs and services, resources and support for ongoing program maintenance costs are usually less available. Thus, a strong community coalition not only provides for ongoing fine-tuning of the service model, but it can also serve as an important source (directly or through their advocacy) for long term funding and support.

MAINE RURAL GERIATRIC DEMENTIA EVALUATION TEAMS

Project Description

As part of the Maine Alzheimer's Demonstration project, Community Health and Counseling Services, a local provider of health care services, developed five evaluation teams to serve four isolated counties in rural, northeastern Maine. Each team consisted of a Social Worker and a Registered Nurse. The teams provided the only dementia evaluation service available in these remote areas. The evaluation includes two home visits by the team, consultation with a geriatric physician, the development of an individualized care plan, and two telephone follow-ups.

Background & Rationale

Most of Maine is rural and sparsely populated. Though it is a geographically large state, there was only one Geriatric Diagnostic center in the central part of the state when the demonstration began. Thus, to obtain an assessment and diagnosis, most of Maine's elderly population had to travel long distances that often included overnight stays. Given the long winters and extreme weather, such travel can be difficult even when feasible. Many families were simply unwilling or unable to travel for this service.

The in-home evaluation team model takes into account the geographic size of Maine. It is an effective way to overcome transportation problems and to increase access to dementia assessment and diagnosis for rural families. In-home assessment also has the benefit of respecting the rural cultural mores of family privacy and "tending out" (taking care of one's own). The assessment process is tailored to each family's needs, which places the family in control.

Project Administration

Maine's Alzheimer's Project (MAP) was created and administered by the Maine Bureau of Elder and Adult Services. Implementation of Rural Geriatric Dementia Evaluation Teams was a collaborative effort between the Bureau of Elder and Adult Services and Community Health and Counseling services.

Project Development

Staff members at Community Health and Counseling Services identified the need for dementia services in rural areas, which they discovered went beyond routine home health issues. To address the need for dementia assessments, the social work coordinator and the geriatric physician developed a proposal for the model of the Evaluation Team, which was funded by the Maine Alzheimer's Demonstration project.

The project began by building community awareness. Letters were sent to all physicians in the four-county service area to introduce the services. Attention was given to communicating with local primary care physicians to encourage referrals and utilization of the service. The presence of the team's geriatric physician was helpful in reaching physicians, and facilitated communication between the doctors.

The service included an initial client visit by the evaluation team, where the team administered a battery of assessment measures and tests. Each team member spent separate time with the caregiver and the elder. Following the visit, the team reported all the information gathered to the geriatric physician consultant. This information included the team's observations of the family living environment, coping strategies in use, and any environmental safety issues or dementia education needs of the family. After reviewing the assessment materials, the geriatric physician and the team conferred by conference call to develop an appropriate care plan. The assessment team made a second in-home visit to explain the care plans and assist the family with its

implementation. The geriatric physician also sent a copy of the care plan to the family's primary care physician and followed up with a call when warranted.

The geriatric physician's approach was very important to the success of the project because his efforts were critical to gaining the trust of local primary care physicians. The geriatric physician presented himself as a consultant with specific expertise rather than as an expert telling the primary care doctors how to treat their patients. He was cognizant of the fact that he had not seen the patient; he had seen only the assessment measures, reports, and test results. Primary care physicians were approached as the "experts" who had seen and knew the family and patients and, often, had been treating members of the family for a long period of time. Consequently the geriatrician was careful to give his recommendations as suggestions and only offer to assist the primary care physicians with their care plans.

Physicians were willing to refer their patients to the service because they had trust in the home health agency and the local dementia evaluation team. The home health agency is a well-known and respected service provider in the four-country service area. Many of the local physicians and team members had prior working relationships through community hospitals and nursing homes. The limited care options in rural areas also encouraged physician referrals. Today, about 35% of referrals come from physicians.

Service capacity has been increased at multiple levels through this project. In the initial phase of implementation, contracts were negotiated with the staff of the only Geriatric Diagnostic Center in Maine to provide training to the social worker and nurse teams. The Home Health Agency now offers dementia training for all social workers, nurses and aides. As a result of this collaboration in care, local physicians have also become more aware of dementia issues. The dementia teams are recognized as local

experts and asked to provide dementia information locally. General community awareness and knowledge has also increased.

Community Partnerships

Partnerships in this project were important, albeit not readily apparent. Foremost, the willingness of individual primary care physicians to work in partnership with the home health agency and with the dementia evaluation team was critical to the success of this service. Had the primary care physicians refused to refer their patients for assessment, or had they ignored the post-assessment suggestions, the project would not have been as far reaching. Likewise, the collaborative approach of the geriatric physician on the evaluation team was important to ensuring the appropriate balance of specialized care and knowledge of the primary care physician in treating the dementia patient.

Finally, the partnership between the State agency and the Community Health and Counseling Services provided the foundation on which this program was built. The pioneering spirit of each of these agencies, the flexibility afforded the providers by the state, and the genuine interest in serving rural elders with dementia proved to be important factors in the project's long-term success.

Barriers & Obstacles

Two significant obstacles were overcome by the project. First, prior to implementation of the project, a general lack of knowledge about dementia prevailed in rural areas among both providers and families. This barrier was partially addressed by a geriatric physician who served as an educational resource to primary physicians. He was the only geriatric specialist outside of Bangor in the four-county service region. Additionally, the assessment teams increased community awareness about dementia by

becoming local resources. Some teams were asked to train staff of residential care facilities on dementia issues and others gave public presentations about dementia.

Second, previous programs designed to serve clients with dementia had been unable to communicate effectively with physicians. Having a registered nurse as a member of the team and a geriatric physician as a consultant to the team was important as it helped to legitimize the medical issues when conveying assessment information to primary physicians. Lack of other options for assessment also may have also contributed to a willingness to use or refer clients to the team.

Project Outcomes & Benefits

This model has been so successful in serving rural families in a sensitive and culturally appropriate manner that the Maine Alzheimer's Demonstration project is planning to replicate the model in other areas of the state. The project has not only brought services to families who would otherwise not be served, but it has successfully served these families within their existing support networks (families do not need to change physicians, etc.). The teams' visits to families' homes provided a first-hand understanding of how the families were coping with dementia issues. Recognition of family and cultural values have heightened the acceptance of the teams by rural Maine families and made the service successful in an environment that is often closed to outsiders.

Having local evaluation teams has also increased the general awareness of the needs of families coping with dementia. There is now a greater likelihood that families will seek help sooner. Having local evaluation teams has also decreased the feelings of isolation previously experienced by many rural families. Family members find it comforting to know someone who understands their situation and can help link them to available resources.

Several journal articles and resources have been produced about this project. Technical assistance is also available for communities interested in replicating the rural geriatric dementia evaluation team concept.

Project Costs & Funding

The cost for the team assessment service in 1999 was approximately \$600 per family. This cost covered two visits by the nurse/social worker team, consultation with the geriatric physician and two follow-up calls by the team. Also included in this estimate are the associated costs for telephone and travel. The social work coordinator, who also oversees the program, provides some in-kind contributions. The coordinator arranges for training and provides information and other support to the teams.

Subsequently, in an effort to reduce the per-client costs, the service was changed so that only one team member returns to make the second in-home visit with the family, instead of both team members returning.

Keys to Success

Six aspects of the project were identified as key to its success:

1. **The project was developed through a partnership with respected organizations** that were already integrated into the service community. This strategy helped to more quickly launch the program. It also helped the project be more accepted by community members, physicians, and other service providers.
2. **Project staff was integrated into other responsibilities.** Staff members who were part of the evaluation team, were full time employees of the agency who had other work responsibilities when not participating in the demonstration project. This practice alleviated financial stress during program start-up or slow times as staff can serve other clients. With abundant funding, perhaps this strategy would be less important. However, few rural service programs have the luxury of

ignoring fiscal realities. Thus, structuring the program so that staff members have ample work when not conducting dementia evaluations was an important approach to ensuring success of the project.

3. **The teams included medical staff to talk with physicians.** As many social service providers know, capturing physicians' attention is difficult at best. Different orientations and language further complicate communication with physicians. Having medical staff on the evaluation teams was essential to getting physician buy-in and utilization of the service. It was also extremely helpful when discussing care plan recommendations and implementation.
4. **The teams traveled to the families, instead of requiring families to travel to services.** The provision of assessments within family homes eliminated the barriers created for rural Maine clients by geographic distances especially in the winter.
5. **In-home visits provided the teams useful insight into the family environment.** For most families, dementia is a disease that affects the entire family. Thus, understanding the family environment in which the elder with dementia is living, the kinds of caregiver support available and not available, and the economic and environmental realities facing the family is important to developing an care plan that will meet the needs of the entire family.
6. **Teams make practical, informed suggestions for behavior management starting with the initial home visit.** By conducting home visits, the team is able to make suggestions that can help families immediately. Through their understanding of the client's home environment, detailed input from the client's primary care physician, and being well-versed in dementia behavior management and rural Maine culture, the evaluation teams were able to make ongoing practical suggestions for behavior management throughout the disease trajectory.

CALIFORNIA'S *EL PORTAL*

Project Description

El Portal is a network of dementia care services for Latino families in Los Angeles, California. The network includes adult day care, caregiver support groups, care management and advocacy, and respite services.

Background & Rationale

Hispanic or Latino residents constitute about 36 percent of the nine million persons who reside in Los Angeles County. The east and southeast areas of the county account for 54% of the state's' Latino population and nearly a fifth of the nation's Hispanics. Nonetheless, before *El Portal* was created in 1992, no dementia specific services were targeted to Latino residents.

Project Administration

The California Alzheimer's Demonstration program was administered by the California Department of Health Services, Alzheimer's Disease Program. The *El Portal* project was conceived and implemented by the Los Angeles Chapter of the Alzheimer's Association, under an Alzheimer's Demonstration Program subgrant from the state. The chapter worked closely with local community members and organizations to plan, develop, and administer the *El Portal* project.

Project Development

To develop services in the Latino community, providers of dementia services consciously set out to become more familiar with the Latino community on the east and

southeast side of Los Angeles. Project meetings were held in the target area to familiarize all partners with the community being served.

Initial service efforts focused on educating local professionals and providers about dementia issues. Media were used extensively to reach the community. Press conferences were held in the Latino community. Advisory groups were developed for outreach efforts and to help inform the community about dementia. Advisory group membership included clergy, representatives from local businesses, caregivers and service providers. Pharmacies agreed to insert *El Portal* postcards in prescription bags. These postcards invited potential clients to use a toll free number to request more information or assistance with specific problems.

One aspect of the program that proved essential to its success was the designation of a key staff member from the Department of Mental Health as the Director of the *El Portal* project. This person, a well-known and respected member of both the Latino community and the service-provider community, spent one day a week in the Los Angeles Alzheimer's Association chapter's headquarters. This strategic integration of staff provided an effective means for educating staff of the Alzheimer's Association and dementia providers about cultural beliefs and differences within the local Latino community. It helped the project gain the trust of the Latino community and gave the project an important link with the formal network of mental health providers.

El Portal staff provided on-going technical assistance to partners during start-up. Partner agencies hosted educational events for caregivers and the public. Brochures were developed with full participation of partner agencies and caregivers. Groups met monthly to assess the content and format of the brochure materials. Representatives of six different Spanish-speaking cultural groups in the target area reviewed the materials for clarity.

In addition to developing new services in the Latino community, *El Portal* trained Care Advocates to assist Latino elders and their families in accessing existing services. Care Advocates are bilingual, bicultural and are from the community. Care Advocates sometimes accompanied case managers on home visits or went with clients to service agencies. Care Advocates were also trained to address family care needs. They have skills in identifying needs, providing dementia education to caregivers and helping with translation. Ongoing, supportive technical assistance from Care Advocates has provided an effective means for increasing service capacity.

Strategic planning and steering committees met regularly to identify and address service issues and to determine how best to support the providers. Quarterly audits of the *El Portal* project provided a structure whereby everyone was informed about unmet needs and new service needs.

Community Partnerships

Initial discussions between state and local providers of aging services had been ongoing for approximately a year and a half before the award of the federal Alzheimer's Demonstration grant. These early discussions helped partners identify their roles and needs. Partners included the California Departments of Health Services, Mental Health, Social Services and Aging, the Los Angeles Chapter of the Alzheimer's Association, and local provider agencies.

For the project to succeed, trust had to be built among the partner agencies and ways had to be found for all participating agencies to work together. All partners had to be honest about the resources they could bring to the partnership, and about the promises they made. It was essential to building trust that organizations not promise services or resources they could not deliver.

The need for trust was also evident when the collaborative partners met to discuss continuing the *El Portal* project beyond federal grant support. This required each partner agency to discuss its own grant funding plans and to collaboratively agree on which foundations would be approached for support for the whole project and which would be most likely to support individual components of *El Portal*. Without the trust that had been developed among all partners, this level of disclosure would not have been possible and the continuation of *El Portal* would have been in jeopardy when the federal funding ended.

Barriers and Obstacles

Critical barriers to collaboration were a lack of knowledge and awareness. At the beginning of the project, there was a general lack of awareness about the extent of dementia in the Latino community. Additionally, there was significant cultural resistance to acknowledging dementia as an illness, as dementia was stigmatized in the community, and Latinos were very conscious of privacy issues. In general, service providers had not previously been familiar with the Latino community culturally or geographically. In addition, because of citizenship issues, some Latinos were apprehensive about government agencies and services. For Latino elders without citizenship, eligibility for service from government programs becomes an issue.

Project Outcomes & Benefits

For Latino families in Los Angeles, a population previously without accessible services, the most important outcome of the project may be the operation of the *El Portal* network for providing dementia services. Indeed, there is now an integrated and comprehensive network of dementia services where none existed previously.

Additionally, a strong and enduring coalition of partnerships within the Los Angeles community have been developed through the demonstration that is ongoing.

Community partnerships have been key to the success of *El Portal*, and developing this type of partnership takes time and money. Thus communities wishing to replicate a program like *El Portal* should be prepared to spend the necessary time and resources, especially during the first two years of the program, to build the indispensable community partnerships and trust.

The development of a replicable process for creating and sustaining the provision of dementia care services in an ethnic community was also an important outcome. Through work with communities in Puerto Rico and Guatemala, it has become clear that the *El Portal* model is replicable in other Hispanic communities. The Los Angeles Alzheimer's Association chapter has taken replication of the *El Portal* success even further by translating the *El Portal* into a successful venture to build a dementia care network in the African American community in Los Angeles. Today, the California Department on Aging and the Los Angeles Alzheimer's Association chapter are collaborating on a new federal Alzheimer's Demonstration grant to further translate the *El Portal* process into the Asian/Pacific Islander communities in Los Angeles and San Francisco.

Finally, through analysis of data collected during the provision of services in this project, substantial knowledge about outreach, delivery, and utilization of dementia services in this Latino community has been gained. While it is clear that each community has its own culture and norms, the lessons learned from *El Portal* have been valuable to numerous other states and communities as they attempt to address the dementia care service needs of their Latino residents. Many resources, most in both English and Spanish, were developed through *El Portal*. These manuals, videos, and other resources are available to communities interested in replicating the *El Portal* model and addressing the dementia service needs of Latino residents of their areas

Project Costs and Funding

The overall costs for developing *El Portal* were substantial, given the magnitude and array of newly created services and the costs of doing business in Los Angeles. About one-third of the annual budget was earmarked for respite subsidies to families. The average annual cost per bilingual care advocate was \$50,000. Legal services were approximately \$22,000 per year. Day care centers offering respite two or three days a week cost \$20,000 per year.

Midway through the federal grant funding, partner agencies formed a work group to collaborate on maintaining *El Portal* after the Alzheimer's Demonstration grant ended. Collaborative grant writing and funding requests had generated \$800,000 (as of 1999) to maintain *El Portal*. Today, the project is self-sufficient, relying on local community funding, client fees, and grants for support. The initial Alzheimer's Demonstration sites are now positioned to receive state funds as the Department of Aging looks to increase the number of adult day care sites in the area.

Keys to Success

Five aspects of the project were identified as key to its success:

1. **Partners had a commitment to serve caregiving families.** Not only was commitment to serving families important to ensure that the funds were maximized, but it was this commitment to families that often helped the partners transcend other administrative, resource, or turf issues and remain focused on the greater goals.
2. **Partners were willing to examine their own beliefs and cultural misunderstandings.** The willingness of mainstream providers to acknowledge their own cultural beliefs and to develop more accurate understandings about the communities they seek to serve is absolutely essential to successful service

delivery in ethnic communities. Commitment from the partners to this endeavor was critical to building trust within the Latino community, and helped to ensure that the dementia services developed met the needs of the families *El Portal* was created to serve.

3. **Partners made a commitment to serve and to collaborate.** Partners learned to trust and rely on each other in service to their shared goal. As has been noted throughout the discussion, the partnerships developed in *El Portal* were essential to success of the project.
4. **Partners were willing to acknowledge and accept their limitations.** While difficult for some service agencies, *El Portal* partners learned that one agency could not be all things to all people. The group learned that through collaboration, a network of dementia services could be created that more appropriately met the various health, social, and cultural needs of the families coping with Alzheimer's disease.
5. **Partners viewed the program as a means to build a dementia services network that would ultimately reduce service costs.** The partners came to understand that through collaboration, agencies could more precisely develop and target their services, thereby maximizing their strengths and cost-effectiveness. When done in collaboration with an entire network of dementia providers, this approach ensured the availability of a full range of dementia care services were available to the community as well as effective targeting of providers' limited resources.

WASHINGTON CLIENT ADVOCATE MODEL

Project Description

The Client Advocate model developed by the Alzheimer's Demonstration Project in the state of Washington was based on the idea that user-friendly and culturally appropriate services are more accessible to minority groups. Client advocates are bicultural and bilingual individuals with dementia training who served as a liaison for the Latino clients who needed adult day care. The primary goal of the project was to recruit and train Latino client advocates to facilitate the use of adult day care programs by Latino clients.

Background & Rationale

The Sea Mar client advocacy model was developed to serve Latino elders with dementia. Prior to the Alzheimer's Demonstration grant, there were no services in the Seattle area targeted specifically to this population. Sea Mar was identified as an appropriate partner and lead agency to implement the project because it was a well-established and highly respected healthcare provider already serving the Latino community. To effectively implement the program, however, Sea Mar needed to collaborate with another service provider with dementia expertise.

While Sea Mar had been serving elderly clients, it had not focused on the needs of Alzheimer's families, nor was it linked with the local network of traditional providers of aging services. In contrast, Elder Health Northwest was a well-established provider of adult day care services with extensive links to the traditional network of service providers. Elder Health Northwest had previously had little success or experience serving the Latino population. By linking these two agencies together, the Alzheimer's Demonstration project was able to enhance the services for the Latino elderly population by increasing Sea Mar's knowledge of dementia issues and linking with mainstream

service providers who in turn benefited from greater knowledge about serving the Latino population.

Project Administration

Washington's Alzheimer's Demonstration program was administered by the Washington State Aging and Adult Services Administration. Development and implementation of the client advocate model was a collaborative effort between the state Aging and Adult Services Administration, Sea Mar Health Services, and Elder Health Northwest's adult day care center.

Project Development

The project began by identifying and approaching the appropriate provider partners. Key individuals from each provider group met to develop an implementation plan. Each partner brought resources to the collaboration as well as a willingness to learn from others.

Elder Health Northwest contributed expertise acquired from a long history of providing adult day care services to dementia families through its established links to the larger network of providers of aging services. It had skilled staff knowledgeable about aging issues and the needs of persons with dementia. The agency staff was motivated by a strong desire to learn better serve the Latino community. The local chapter of the Alzheimer's Association of Western and Central Washington contributed knowledge about dementia and provided resource materials prepared in Spanish.

Sea Mar began by identifying and training client advocates. Bicultural and bilingual individuals who were members of the Latino community were selected. These individuals were characterized by a desire to help their community and by a caring attitude. They were provided with technical support, on-going training, and encouragement throughout their employment. Client advocates were involved with

outreach efforts and the daily tasks of the adult day care program, but their main priority was to help integrate the Latino clients into the day care setting. Additionally, the client advocates shared knowledge of the Latino culture with the day care staff and helped other staff to become more comfortable with serving the Latino clients. The client advocate also led some activities at the adult day care center in Spanish or both English and Spanish helping clients from different backgrounds engage in common activities and further client integration. Moreover, they advocated for their clients within the broader service network (Social Security benefits, Medicaid, Medicare, etc.).

To a large degree, the success of the project depended upon the willingness of participating adult day care centers to be flexible, open to change, and willing to re-think and alter protocols for service delivery. Success was achieved by integrating services rather than by operating two separate programs under one roof. Strategies for developing and implementing culturally appropriate and balanced programs had to be worked through and negotiated among partners. The host day care agency had to be willing and committed to serving the Latino community. Centers had to be more flexible in their intake processes and sometimes even began serving the client before all application forms were completed. Processes and practices had to be assessed and renegotiated on an on-going basis.

Community Partnerships

The newly formed partnership of providers developed the capacity to serve Latino clients very efficiently. Both Sea Mar and Elder Health Northwest were well-established and well-respected community organizations dedicated to serving older persons. Thus, the process of developing partnerships for implementing the client advocate model was not as difficult as if the agencies had been unknown to each other. However, as with any partnership, developing a good working relationship and common

understandings and approaches took time and commitment. The partnership was refined over time and has resulted in a mutual exchange of information, ideas, knowledge, and respect.

Barriers & Obstacles

To effectively implement the care advocacy model, the general Latino community needed to be made aware of dementia issues and the services available to meet the needs of Alzheimer's families. Outreach was accomplished through television and radio announcements. In addition, brochures were placed in locations throughout the community frequented by elderly persons or their family members. These locations included grocery stores, churches, restaurants, banks, health clinics, and nutrition sites. The general lack of awareness of dementia in the community contributed to stigma and misinformation in the community.

For outreach efforts to be effective, providers needed to be very conscious of privacy issues. Trust had to be built in the community for the adult day care program. Additionally, trust needed to be developed between the Latino clients and the client advocates. Client advocates focused on building rapport and trust with each client. One way of developing client trust was to try to address each client's immediate needs as quickly as possible. This often entailed locating support services and linking clients to those services before suggesting use of more formal services such as adult day care.

Project Outcomes & Benefits

The Client Advocate model is a cost-effective means of overcoming cultural and language barriers in serving a minority population. Its legacy is the creation of strong community partnerships that have resulted not only in increased service capacity but also in enhanced services.

Each partner has experienced benefits from involvement in this program through enhancement of its service capacity. Partner agencies have learned from each other and their own programs have been enriched. Many of the client advocates, initially trained for this project, have been hired as permanent staff members of the adult day care center. Elder Health Northwest has essentially integrated the Client Advocate model into its established day care programs. The agency has learned how to provide services to the Latino community by overcoming cultural barriers.

Sea Mar has adapted the Client Advocate model to other service programs including meal sites and rural adult day care settings. Additionally, the outreach efforts to the larger Latino community have increased knowledge and awareness of aging and dementia issues within the community.

The client advocate model is a concept that was used in Washington with several other ethnic groups, and has been replicated in other communities across the country. Washington has won an award for exemplary programming in outreach to minority elders from the Western Interstate Commission on Higher Education (WICHE) and has provided technical assistance to replicate the model in the Netherlands.

A video and training materials have been produced by the State of Washington Aging and Adult Services Administration and are available to communities interested in learning more about the client advocate model.

Project Costs & Funding

The limited resources available for this project were used to employ the client advocates. In-kind resources were used to cover all other costs such as telephone, travel, and translation of materials.

To replicate this model, communities should have sufficient funds to support a full-time client advocate position, paid at a social service paraprofessional or

professional entry-level salary. It is also necessary to identify resources to provide on-going technical support for the client advocate and conduct cultural training for service staff. Outreach efforts should be conducted in appropriate languages using multiple types of media and extend to a broad geographic location. Equally important, service providers should be flexible about assessment, eligibility, and income requirements.

Over a period of time, the costs of the client advocates have been incorporated into both Elder Health Northwest and Sea Mar's operating budgets. The work performed by the client advocates was recognized by both agencies to be so important that each has found ways to maintain the advocate services beyond the demonstration funding. Most of Sea Mar and Elder Health's services are currently funded through a combination of state and federal grant monies, client fees, third party reimbursement, donations, and foundation grants.

Keys to Success

Five aspects of the project were identified as key to its success:

1. **Partners were willing to re-examine their own beliefs and cultural misunderstandings.** As in other successful Alzheimer's Demonstration projects, the willingness of the partners to examine their own cultural beliefs and appropriately adjust their practices was key to the success of the client advocate model. As the partners' attitudes changed, so did the programming and approach to service delivery, resulting in more culturally appropriate services attractive to Latino families.
2. **Partners began with an understanding that the traditional way of doing things may not be the best way to serve a minority community.** This understanding that approaches and processes might have to be altered to successfully serve the Latino dementia population was important because it

- helped the partners remain open to new ideas, new approaches, and non-traditional activities.
3. **Integrating two cultures into a service program required flexibility from both cultures.** When attempts are made to combine two existing systems, competing views and turf issues sometimes block the success of the effort. This barrier was overcome because each group (Sea Mar and Elder Health Northwest) was open to “giving a little in order to gain a lot”. This mindset and approach proved priceless to the overall success of the client advocate model.
 4. **The heart to heart connection among staff and clients made all the difference.** When we’re feeling ill or are confused, we generally want a comforting voice, a reassuring touch, and to know that somebody we trust is in “our corner” looking out for our best interests. Nothing could be truer in the Latino community in Washington, especially when dealing with elders with dementia. Thus, the personal connection between the staff and clients was often a major factor influencing a client’s decision to use the services they needed.
 5. **A commitment to serve was the most important element.** When all is said and done, there will be plenty of obstacles and reasons in the beginning to discontinue a collaborative endeavor. However, an overarching commitment to provide quality service to a population of individuals who desperately need assistance can help to overcome many barriers. This proved to be the most important factor in ensuring the success of the client advocate model.

WASHINGTON, DC AL-CARE

Project Description

The AL-CARE Program has successfully served persons with Alzheimer's disease who live alone in the District of Columbia (DC) for more than nine years. Before the AL-CARE experience, few providers considered living alone in the community a viable option for people with Alzheimer's disease. The type of service provided to AL-CARE live-alone clients is not very different from traditional home care services (personal care, basic health, meal prep, etc.) with the exception that more cueing and supervision may be necessary for tasks such as eating and going to day care.

Background & Rationale

When the District of Columbia Office on Aging asked their service network providers to identify an underserved dementia population in the District of Columbia, it was discovered that there were numerous persons with dementia living alone. At the time, AL-CARE was the only home care program exclusively serving clients with dementia. Because of AL-CARE's focus on caregiver respite, individuals without live-in caregivers had previously not been eligible for the services. With the advice of members of DC's Senior Network, the District of Columbia Office on Aging proposed to use the federal Alzheimer's Demonstration funds to target the live-alone population. More than half of AL-CARE's clients served throughout the duration of the federal grant lived alone.

Project Administration

Washington, D.C.'s Alzheimer's Demonstration program was administered by the District of Columbia Office on Aging. The development and implementation of the AL-CARE live alone program resulted from a close collaboration between the DC Office

on Aging and AL-CARE, a local provider of in-home health and personal care services specifically focused on serving persons with dementia.

Project Development

Most service providers in the District of Columbia area were well aware that there was a large, unserved population of elderly persons with dementia who were living alone in the District. Following a survey sponsored by the District of Columbia Office on Aging, providers acknowledged that the population existed and agreed to make the commitment to serve them. As the only home care agency in the area specifically focused on serving people with dementia, AL-CARE was the natural choice as the lead provider agency for the project. Additionally, as AL-CARE was already a trusted and participating member of the provider community, issues of trust building and awareness did not warrant special attention.

AL-CARE initially expanded its base by serving individuals with live-in caregivers who were at work or otherwise out of the home during the day. AL-CARE distributed a brochure in the community that described its services to live-alone clients. Using the Senior Network communication structures (newsletters, quarterly meetings, etc.) providers were notified of AL-CARE's new focus. The agency began receiving referrals soon as providers became aware of the service availability. Thus, AL-CARE had very little start-up time and was at full capacity soon after the Alzheimer's Demonstration grant was awarded.

AL-CARE and the District of Columbia Office on Aging are now working with other providers in the Senior Network to encourage them to begin providing services to the live-alone population.

Community Partnerships

Community partnerships are always critical to the success of an Alzheimer's Demonstration project. AL-CARE was no exception. In addition to the partnership developed between the AL-CARE service agency and the DC Office on Aging, the long-standing partnerships within the Senior Network in the District were important to ensuring the success of this project. The Senior Network includes over 30 agencies funded by the Office on Aging that provide service in over 100 sites. AL-CARE has been a member of the Senior Network in the District of Columbia since 1986. Since the Senior Network was operating effectively when the DC Alzheimer's Demonstration project began, there was far less work to do in the partnership and community trust development phase than did other Alzheimer's Demonstration projects.

Barriers & Obstacles

One of the key barriers to providing services to the live-alone population was skepticism within the community at large that individuals with dementia could or should live alone in the community. Overcoming this attitude was essential to gaining broad-based community and family support for the live-alone project.

Serving persons with dementia takes special attention compared to traditional home health clients, but serving persons with dementia who live alone takes additional commitment and patience from, and support for, the home health aide. Specialized training and supports were developed to ensure that the aides had the skills and back-up necessary to be successful.

Provider liability and service agreement issues also had to be handled differently, because there were no live-in caregivers to give consent. For example, it was necessary for AL-CARE to change their consent forms that had been geared toward a population that lived with a caregiver. It was sometimes necessary to find relatives or

other persons responsible for live-alones to give consent to serve those clients who were not mentally competent to enter into service agreements. Access to homes had to be negotiated in different ways, because live-alone clients may not remember to be home for, or to let in, their home care workers. Home care aides had to be constantly vigilant about safety issues, which were more prevalent in this population given that there was no caregiver at home to assist the individual with dementia.

Home care was generally provided until the Case Manager, the family, or the guardian decided that it was unsafe for the client with dementia to continue living alone. Families generally arrived at such a decision due to excessive wandering by the client, deterioration in the client's physical health, or extreme problems with personal hygiene (i.e. uncontrollable bowel incontinence).

Project Outcomes & Benefits

In addition to offering a low-cost service to a segment of the population that previously had few options, the AL-CARE live-alone project broadened awareness about dementia and helped alleviate the misconception that persons with dementia cannot live alone. Based on AL-CARE's success, several additional communities are now working to serve persons with dementia who live alone.

Working closely with Duke University and the Alzheimer's Association, a manual and video on how to work with people with dementia who live alone was produced. These resources provide the necessary information and resources to develop live-alone dementia services in other communities.

Project Costs & Funding

In 1999, the average live-alone client used approximately \$3,000 per year of AL-CARE services. This compared to \$165 per day for nursing home care, which is the only other option available for persons with dementia who live alone in the District of

Columbia. In the later stages of Alzheimer's disease, the need for care becomes extensive. Clients who required more care than was subsidized by the Alzheimer's Demonstration project purchased additional services at private pay rates. The agency has received more than \$40,000 in contributions from relatives or financial guardians of live-alone clients. Stories of live-alone situations have been effective for fundraising. AL-CARE regularly applies for grants from foundations and other organizations with interests in supporting programs for persons with dementia who live alone.

The costs for expanding the program included additional training for home care aides, increased professional staff support, and flexible scheduling. Increased training and supervisory costs are minimal and can be incorporated into existing training protocols with existing staff. However, flexible scheduling may lead to increased costs, depending upon how an agency compensates its home care aides. There are occasions when a home care aide may go to a client's home only to find the client absent or unwilling to let the aide into the home. Provided the home care aide makes every effort to find the client or gain access to the home, the AL-CARE home care aide is paid for the whole visit, regardless of whether the aide got into the home or not. These paid visits can become expensive because this situation occurs, on average, about three times a month with live-alone clients served by the District of Columbia program.

Keys to Success

Five aspects of the project were identified as key to its success:

1. **Make a commitment to serve clients with dementia who live alone.** AL-CARE found that it was not as difficult as previously thought to serve persons with dementia who lived alone. However, the approach to service delivery is different and takes a commitment to ensure that ethical, legal, and safety concerns are addressed.

2. **Hire and train appropriate aides.** The success of the AL-CARE program is directly related to the quality of their home care aides. Providing appropriate training and support was essential to the project's success. Flexible scheduling, training, paying for time spent searching for a client were all important personnel policies in this project.

3. **Ensure that aides are absolutely honest, sensitive, and caring.**

Communities and families are already skeptical about the ability of home care agencies to serve persons with dementia who live alone. In part, one of the concerns is the vulnerability, financially and personally, of the person with dementia, especially when no caregiver is available to protect the client's interests. It is, therefore, critical that aides who serve persons with dementia who live alone are beyond reproach with regards to honesty and integrity, and that they exhibit a sensitive and caring nature. Nothing will sink a program quicker than distrust or allegations of illegal conduct among the staff.

4. **Emphasize the importance of good communication skills in training aides.**

Persons with dementia clearly have memory problems and often have communication problems. Thus, it is essential that the aides are effective communicators – with the clients as well as with any family or community members involved in the client's care. For persons with dementia, good communication skills often include extraordinary patience and flexibility. A solid understanding of effective communication techniques with persons with dementia is an important component of training for home care aides.

5. **Ensure that everyone is flexible and creative in meeting various needs.**

Serving persons with dementia who live alone requires a high level of flexibility and creativity – both from the home care aides as well as from the home care

agency and staff supervisors. Unlike non-dementia clients for whom routines can generally be established and are usually adhered to, people with dementia who live alone are less predictable and less likely to remember schedules, routines, and requirements. As such, aides must be given the autonomy and flexibility necessary to manage situations as they arise. The home care agency's personnel policies must acknowledge the environment that aides often find themselves in and supervisors must ensure that appropriate technical and emotional support is provided to everyone involved in the care of those working with the live-alone clients. Finally, funding agencies must be flexible to allow full development of the live-alone option, recognizing that service delivery to persons with dementia who live alone may require slightly different parameters than traditional home care services.

CONCLUSION

Through the efforts of the partners in the fifteen state projects of the national Alzheimer's Demonstration Program, much has been learned about working with families coping with Alzheimer's disease. In particular, the Demonstration program has been very successful in developing innovative approaches to serving "hard-to-reach" and traditionally underserved populations. The five highlighted exemplars are just the "tip of the iceberg" of the wealth of understanding generated through the Demonstration program. Not only have the Demonstration projects helped us better understand how to serve persons with Alzheimer's disease more appropriately and inclusively, but significant local collaborative relationships and partnerships have been created as well.

One particular key to success in the Demonstration program was the cooperative orientation between the Demonstration Evaluation Team and the state project directors.

The approach provided for continuous program refinement that significantly supported states' ability to pass new legislation and leverage new funding. By sharing data and preliminary evaluation findings on a regular basis throughout the program, project directors at the state level were provided with resources to better understand their service population, refine their services, identify service gaps in their projects, and improve their service systems. Indeed this form of research, often called "action research," is one of the few strategies that embrace the concepts of participation and empowerment of those who seek to improve their social situation.

The partnership between the Evaluation Team and state project directors was only one of many critical partnerships in each local project. Generally, the process of building strong partnerships created trust and support from respected members of the community, and this trust was essential for generating awareness and acceptance of new services within minority ethnic communities. The simple availability and awareness of respite care services, however, did not necessarily result in the use of such services. Project staff found that successful promotion of the program required both time and effort contacting and partnering with key community leaders. Significant community education about dementia and staff education about cultural norms and approaches was essential to successful service delivery in all ethnic communities.

Staff and community education was also essential for project success in rural communities. Ongoing technical support for outreach, training and educational efforts was found to be particularly useful for projects in remote rural areas that tend to be isolated from educational opportunities and resources. While all new programs benefited significantly from training programs for their own staff and for staff of service partners, the opportunity to gain additional training and resources was found to be especially valuable to rural providers.

Appropriate cultural approaches, community and staff education, and the development of community partnerships were all important steps towards ensuring longevity of demonstration project services. One of the primary goals of the Alzheimer's Demonstration Program is to facilitate the development of services and systems that continue beyond the initial federal grant period. Although there was variation across the fifteen grantees in stability and longevity of programs, the final reports of most of the grantees indicated that at least some portion of state or local support services initiated under the auspices of the Demonstration was expected to continue to operate after the federal grant ended.

States have taken several approaches to fostering support and funding for the continuation of services. In some states, demonstration services have been integrated into existing service systems and they continue to operate under existing state or local program authority and funding. In other states, the coalitions of service and advocacy agencies that emerged through state demonstration projects have been successful in developing new resources, both public and private, to support continuance of Demonstration services. In several cases, these coalitions were so successful that new state legislation focused on supporting persons with Alzheimer's disease and family caregivers has been enacted.

In 2000, as part of the reauthorization of the Older Americans Act, Congress enacted the National Family Caregiver Support Program (NFCSP). While designed to serve all caregivers, those families whose loved ones have Alzheimer's disease will surely benefit. Findings from the Alzheimer's Demonstration Program were used in the design of the NFCSP, and the two programs are being closely coordinated in most of the states that have Alzheimer's Demonstration grants. The lessons learned in the Alzheimer's Demonstration Program have already proven useful in many communities during implementation of the NFCSP. Developing local coalitions, outreach to ethnic

and rural communities and resource building have proven to be important concepts in the new NFCSP as well. As we evaluate the impact of the NFCSP and the development of services for family caregivers, it will be interesting to compare the similarities and differences of the developmental phase and long-term success of the NFCSP to that of the national Alzheimer's Demonstration Program.

The partnership among the Administration on Aging, the Evaluation Team, state staff, the Alzheimer's Association and the incredibly dedicated individuals in the field has resulted in the development of a wealth of information to impart to others who share the goal of improving the lives of individuals with Alzheimer's disease and their caregivers. As we continue to learn more about Alzheimer's disease, it is our hope that one day a national program dedicated to developing services for people with Alzheimer's disease will no longer be needed. Until then, we will continue to deliver culturally appropriate, accessible, and affordable home and community-based services to Americans with Alzheimer's disease and their families. For more information, recent evaluation reports, and new resources developed by current Alzheimer's Demonstration Program grantees, please visit the Administration on Aging's Alzheimer's Resource Room at <http://www.aoa.gov/alz>.

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